Parent Professional Partnerships in Medical Homes and Health Reform

Deborah Garneau,
Special Needs Director, RI Department of Health
Lisa Schaffran,
Associate Director, RI Parent Information Network

THE PARADIGM SHIFT

- States and local governments are mandated to ensure access to care that is person/ family-centered, easy to use, culturally competent
- States and local governments are decreasingly direct service providers
- Affecting CHANGE
  - Contracting versus Integrating Parents

→ → → →

Administered by----------Contract to Provide----------Family Resource Specialist Services

RI's Medical home Initiative is launched!

The Pediatric Practice Enhancement Project (PPEP) was developed to enhance Medical Homes in RI.

Where do families go for Information and support?

•Parents/Families with CSHCNs go to their doctor as a trusted source of information
•Parents/families seek each other for information, as those who know resources and have unique knowledge of navigating systems

The PPEP Model blends the where families go for accurate information and places and pays for trained Family Resource Specialists in Medical Homes throughout RI.

2004: 8 practices – primary care
2006: 20 practices – primary and specialty care
2008: 24 practices – added healthcare centers
2013: 30 practices; 15 agency based; 5 resource center

Who are the Family Resource Specialists?

Parents and family members who have CYSHCNs and individuals with SHCNs who have experience in navigating the complex systems of care in Rhode Island. This experience includes knowledge of resources: from information re: basic needs (food, shelter, clothing) to accessing the appropriate insurance plan or specialty evaluation.

How does the FRS meet families?

•Referrals from physicians, staff, other families, meet in waiting room, health plan referral, coordinated chronic condition workforce partner referral

Where are the FRS located?

•They are located in the physician's offices, at RIPIN or other community based organizations, and at health plans

What does the FRS do?

•Addresses the needs of the child and family: education, health insurance, basic needs

•Follow up on referrals to specialists

We <u>did not</u> create any new services and program – we coordinated and linked to existing supports, services and programs

How do we measure success?

Individual Level Evaluation

- Demographics / General Information: Age, Diagnosis, Race, Ethnicity, # in Household, Problems Identified
- Process Measures: Activity Type, Activity Location, Activity Content, Time Spent
- Outcomes: Goal Achievement, CEDARR Referrals, Referrals Made & Type, Utilization Analysis

In 8 years:

- √ Served nearly 9000 CYSHCN and their families
- √ Had 35,094 contacts with families
- √ Addressed 22,020 family concerns
- √ Assisted families in achieving 89% of concerns
- √ 40 Resource Specialists are currently working on 750 concerns
- ↑ Understanding of service system
- ↑ Satisfaction with care
- ↑ Feel empowered & supported
- ↔ Change in utilization of health care

√ Categories of Problems Addressed:

22% Education
19% Mental / Behavioral Health
17% Specialty Evaluation
9% Health Insurance
7% Recreation / Social
7% General Parenting
5% Housing
4% Food / Clothing
4% Nutrition
3% Medical Equipment
3% Child Care

Practice Level Evaluation:

- Identification of CSHCNs within practice
- Track and monitor CSHCNs
- Practitioner productivity
- Comprehensive service delivery / provision

Practice Level Results:

↑ Physician Productivity

↑ Patient Satisfaction

↑ Physician Satisfaction

↑ Comprehensive Care

↑ Knowledge of System

↓ Family Wait Time

↑ FAMILY CENTERED CARE

System Level Evaluation:

- Systems Barriers identified and worked on
- Integrated Service Delivery System for CSHCN and their families
- Practices Buying-In
- Recognition as a Reimbursable Service!

System Level Results

CEDARR works better

Reduce Wait Lists

Increase in Family Education

Identified Need for Coordinated Information

INTEGRATED SYSTEM OF SERVICES

Peer Navigators in Community of Care

Health Insurance Exchange Partner

Consumer Assistance Program for ACA

THE EVALUATION of PPEP

- **Evaluation Partners: Center for Health Data & Analysis, Brown University, Neighborhood Health Plan of RI**

- **Conducted a utilization analysis**
  - **Pre-PPEP**
  - **PPEP**
  - **CSHCNs Non-PPEP**

- **Compared 3 groups of utilization of healthcare by location, outcomes and utilization cost (ED, inpatient, outpatient).**

PPEP Evaluation Summary

	Total CYSHCN	ED Visit # (%)	Hospital Stay # (%)	OP Visit # (%)	Ave Cost Per CYSHCN
Pre-PPEP	355	339 (95.5%)	176 (49.6%)	5,550 (15.6%)	$23,842
PPEP	353	262 (74.2%	89 (25.2%)	4387 (12.4%)	$14,593
Std Care	2,024	1,384 (68.4%)	1,191 (58.8%)	20,864 (10.3%)	$19,858

Key Elements to Success

- **Families have comprehensive needs that affects utilization of health care.**
- **Family workers / peer resource workers need to be supported (ie, paid, trained, supervised)**
- **Need a comprehensive system of care to address needs at all levels:**
    - **State / policy level**
    - **Practice / community level**
    - **Individual / family level**

Opportunities for peer support under the ACA

- Consumer Assistance Center
- Patient Navigation
- Community Health Worker
  - Direct patient assistance
  - Attending to the social determinants that interfere with health
- Coordination of training
- System Support

Questions? Comments

Deborah Garneau, Special Needs Director, Health Disparities & Access to Care Team,

RI Department of Health, 401-222-5929, deborah.garneau@health.ri.gov

Lisa Schaffran, Associate Director, Family Voices Program Director, RI Parent Information Network, 401-270-0101, schaffran@ripin.org

Parent Professional Partnerships in Medical Homes and Health Reform

Deborah Garneau,
Special Needs Director, RI Department of Health
Lisa Schaffran,
Associate Director, RI Parent Information Network

Transition, Families, and Youth-Essentials in the Medical Home Neighborhood

Pennsylvania Medical Home Initiative

A statewide quality improvement initiative for children and youth with special health care needs

Lizanne Welding Mills, MS, MBA
Transition Coordinator-PA Transition MH Program

Erin Campion, M. Ed.
Parent Advisor-PA Transition MH Program

Molly Gatto, MHA
Program Director, Pa Medical Home Program

Renee Turchi, MD, MPH, FAAP
Medical Director, PA Medical Home and Transition Program

DEPARTMENT OF HEALTH

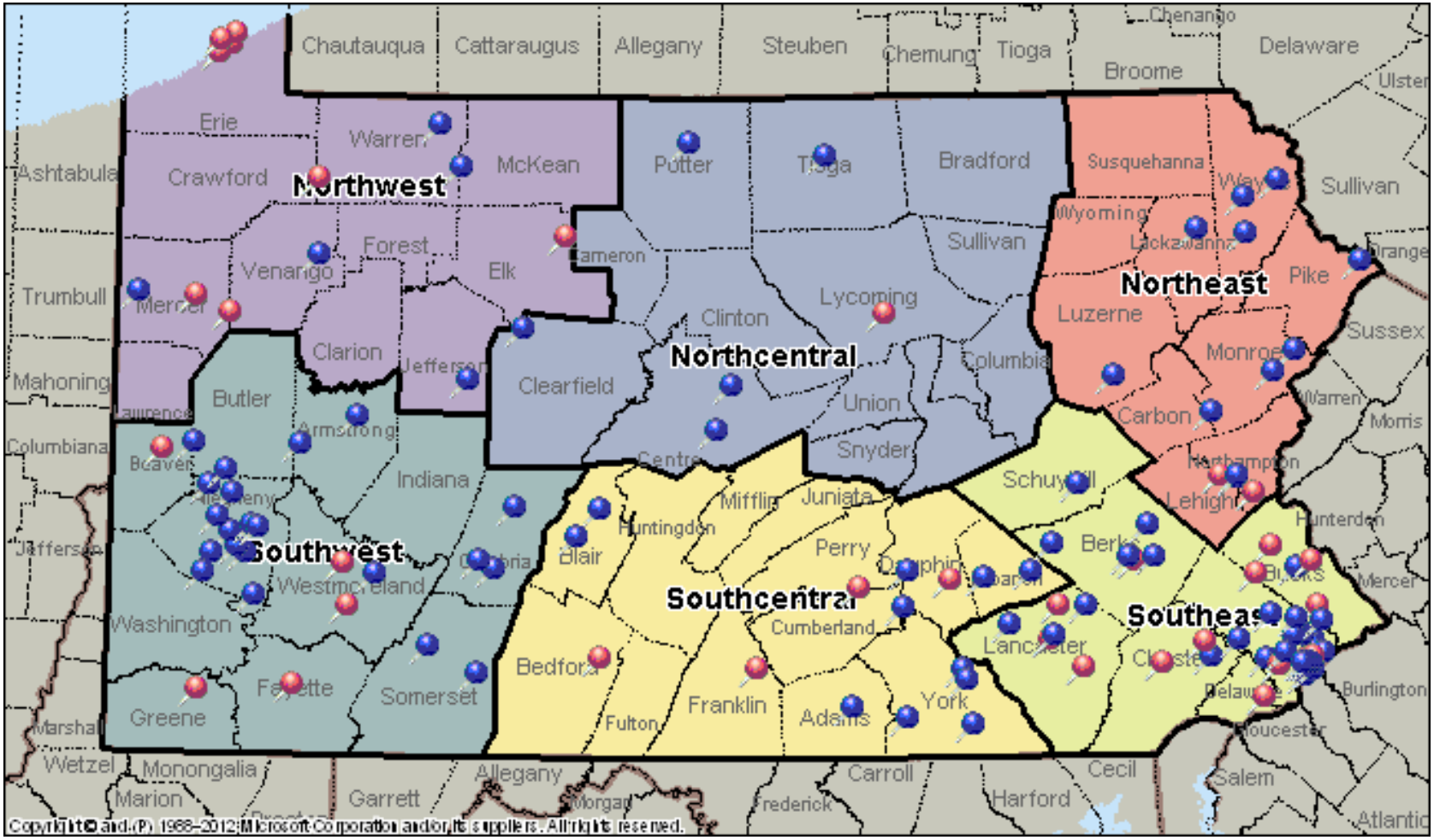
U.S. Department of Health and Human Services
HRSA
Health Resources and Services Administration
Maternal and Child Health Bureau

The Medical Home Initiative

The PA Medical Home Initiative

- Built upon the AAP Medical Home framework and Joint Principles tenants
- Emphasizes QI, practice transformation and family centered care, communication and community partnerships
- Largest pediatric network of medical home practices- 165 pediatric practices trained in PA
- Practices participate via: quality improvement teleconferences, bi-annual conferences, and education and technical assistance from the MHI team at the PA AAP

Medical Home Sites



Participated in Medical Home implementation

Has received Medical Home Outreach/Education

There are 92 sites that have participated in implementation (navy dots) and 42 sites (pink/red dots) that have received education marked on this map dated 1/24/2013. Some pushpins may overlap when sites are in close geographical proximity.

PA MHI Transition Program

PA Transition Efforts

1.) Funding:

- Innovation Grants (MCHB)
- Priority 9 (PA DOH)

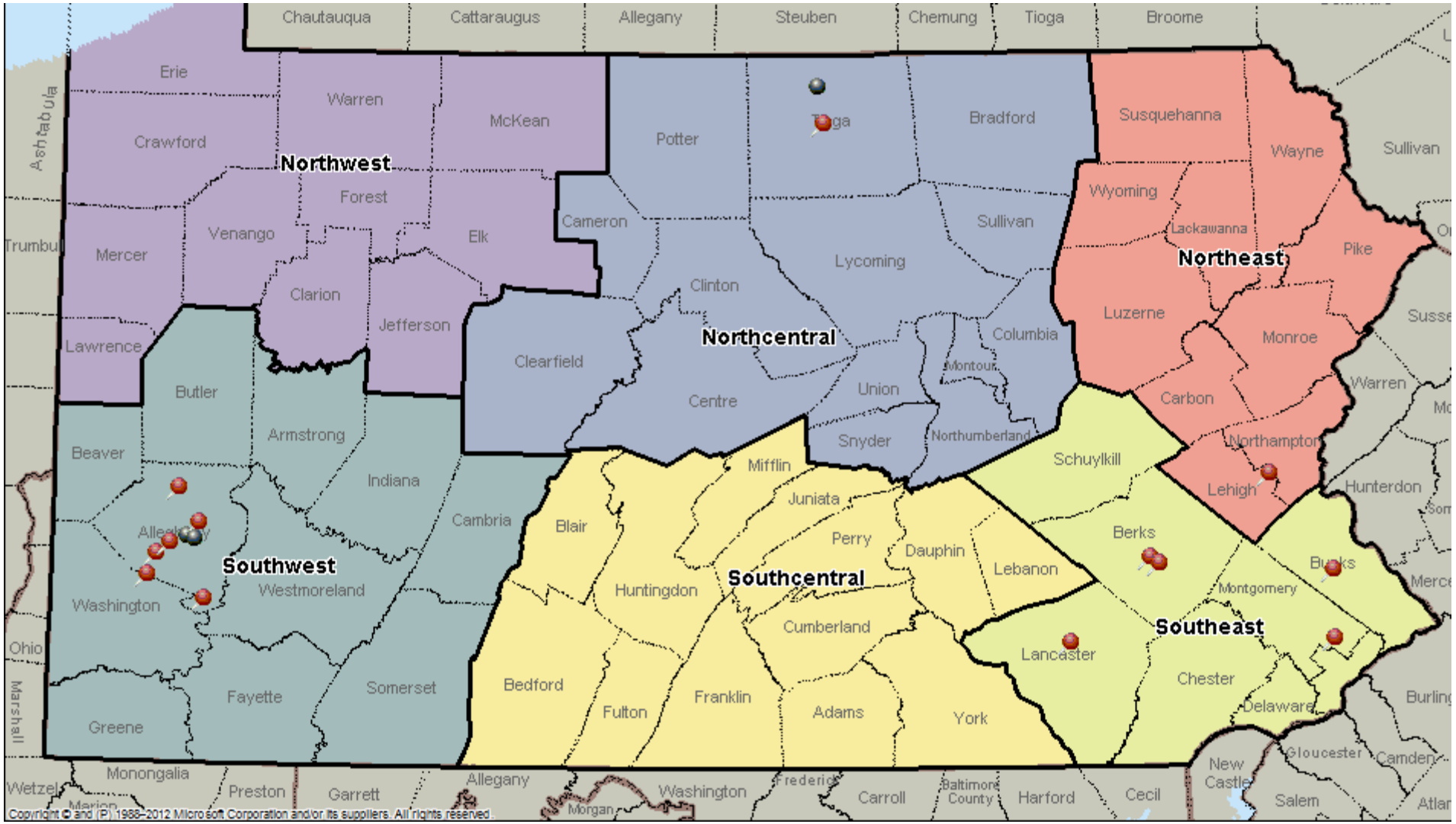
2.) Activities include:

- Work with practices initiating transition work and six core measures of transition
- Collaboration with National Centers, community partners, and families
- Identify and work with adult practices
- Test “Ops Memo” Policy

Six Core Measures of Transition

Pediatric Health Care	Adult Health Care
1. Transition Policy	1. Young adult privacy and consent policy
2. Transition youth registry	2. Young adult patient registry
3. Transition Preparation (readiness assessment)	3. Transition preparation
4. Transition Planning (action plan, care and emergency plan, medical summary)	4. Transition Planning
5. Transition and transfer of care (HCT summary and transfer of care checklist)	5. Transition and transfer of care
6. Transition completion (strategies)	6. Transition completion

Transition Practices



Adult Transition Practices as of 1/24/13

Pediatric Transition Practices as of 1/24/13

Family and Adult Provider Surveys

PA MHI Family Survey

Areas measured on the survey:

- Components of Medical Home
- Accessibility
- Parental satisfaction/trust
- Health care utilization
- Unmet medical needs
- Demographic information

Family Survey Summary: findings relative to transition

- Only 52% of pediatricians have talked to families about how a youth's needs will change when they become an adult
- Families would like more information on health insurance coverage, long term care plans, and jobs or vocations
- Only 32% of pediatricians have developed a plan to deal with the youth's health needs as they get older

Challenges

Pediatric Practices working on transition report:

- Navigation through a large health care system can be difficult
- Some families are not ready for the change
- Paucity of adult providers that accept young adults with highly complex medical histories
- Parents want to talk about their feelings: they are afraid the adult care system will not be responsive to their young adult's special health care needs

Challenges (cont.)

- Parents want assistance finding adult PCPs and specialists who are familiar with special needs clients
- Want reassurance that we will assist them with record transfer and be available to the new provider to discuss their young adult
- Transition concept difficult for both patient and provider and for other personnel in the practice
- Reviewing and choosing/creating materials very time consuming

Adult Provider Survey

- Created via Special Needs Consortium

- Objectives:
  - identify adult providers and their capacity to treat YSHCN
  - Describe challenges of adult physicians and provide educational opportunities

As of early 2012, 170 surveys have been completed representing 19 of Pennsylvania's 67 Counties

Survey Results

- 7% had a wheelchair scale
- 40% have exam tables that raise and lower
- 79% are familiar with medical home principles, but only 18% have patient partners
- 46% utilize a care plan for their patients
- 53% utilize patient registries for YSHCN

Survey Results (cont.)

- What do adult physicians need to care for YSHCN:
  - Protected staff time
  - Access to appropriate specialists
  - Enhanced reimbursement
  - Increased knowledge of community resources and supports
  - Additional training on specific diagnoses

Partners, Policies, Benefits and Tools

Community Partnerships

- Collaboration with:
  - Elks Home Service Program
  - Centers for Independent Living
  - Office of Vocational Rehabilitation
  - PA Chapter Family Physicians
  - College of Physicians
  - Leadership Education in Neurodevelopmental Disabilities Program (LEND) – Children's Hospitals of Philadelphia and Pittsburgh
  - Parent Education, Advocacy and Leadership Center (PEAL)

Parent Education Leadership & Advocacy Center (PEAL)

Creation of a series of videos addressing the following topics:

1. Self Determination
2. Individualized Health Plans
3. Health Insurance and Service Eligibility
4. Moving On
5. The Ops Memo

Videos are available this at:
www.pamedicalhome.org

Ops Memo on Transition

- Contractual agreement between PA DPW and the Medicaid managed care companies
- Enables a youth of transition age to have visits with an adult provider without changing his pediatric primary care physician
- Facilitates youth finding the “right fit” to enhance successful transitions
- Eases the burden on the adult provider by staging the transition
- Copy is provided in your packet

Tools

Readiness assessments/tools for families:

- Parent Intake form
- Florida HATS On Traq Tool
- PA DOH Checklist
- Satisfaction survey

Tools for Practices:

-Transition index

-Transition Care Plans

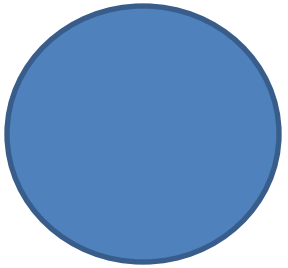
Resources

Considerations:

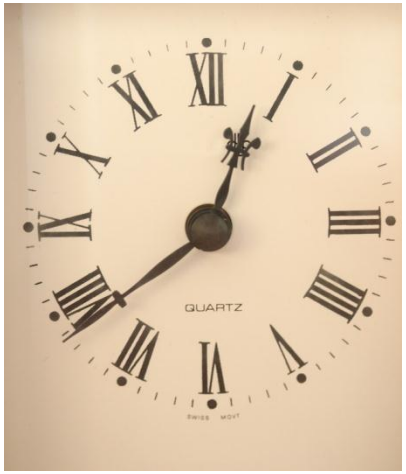
- Guardianship/power of attorney concerns
- Waivers
- Insurance
- Education
- Transportation
- Vocation and employment
- Independence and self care

Parent Advisors

- 360 °
  completing the perspective



- 24/7
  making the connection



Benefits for Adult Primary Care Providers

- Meets ACP and AAFP criteria for maintenance of certification
- Enhanced communication and informed patient transfers
- Potential funding for practices over two years
- Linkage to adult and pediatric experts on transition

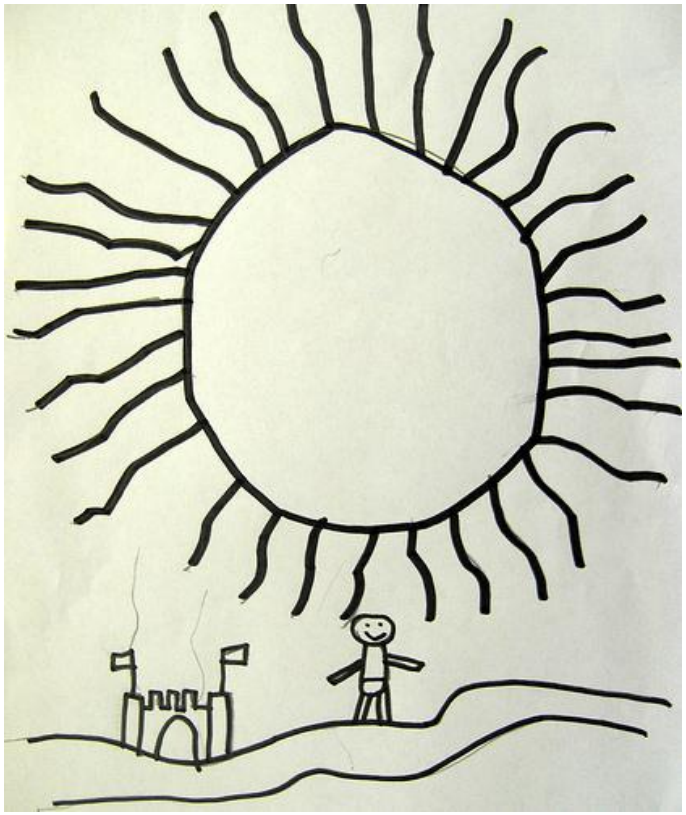
Benefits for Adult Primary Care Providers cont.

- Enhancement of quality improvement in the practice
- Access to wealth of resources through the AAP MHI team, including Parent Advisors
- Prepared youth and families ready to enter adult-oriented system of care

Thank you

- Children/youth and their Families
- Grant support
  - Maternal Child Health Bureau
  - PA Department of Health
- PA AAP and partners (NCCC, Got transition, PEAL (F2F), LEND
- Pediatric and adult practices participating in the PA Transition and Medical Home initiatives

Thank you!



Please keep building.
Everyone deserves a medical home!

Photo by maureen crosbie
http://www.flickr.com/photos/maureencrosbie/3273777533/

Contact information

- Lizanne Welding Mills, MS, MBA
  Transition Coordinator
  484-446-3064
  lmills@paaap.org

- Renee Turchi, MD, MPH
  St. Christopher's Hospital for Children, Philadelphia, PA
  215-427-5331
  renee.turchi@drexelmed.edu

- Erin Campion, M. Ed.
  Parent Advisor
  484-446-3064

Transition, Families, and Youth-Essentials in the Medical Home Neighborhood

Pennsylvania Medical Home Initiative

A statewide quality improvement initiative for children and youth with special health care needs

Lizanne Welding Mills, MS, MBA
Transition Coordinator-PA Transition MH Program

Erin Campion, M. Ed.
Parent Advisor-PA Transition MH Program

Molly Gatto, MHA
Program Director, Pa Medical Home Program

Renee Turchi, MD, MPH, FAAP
Medical Director, PA Medical Home and Transition Program

DEPARTMENT OF HEALTH

U.S. Department of Health and Human Services
HRSA
Health Resources and Services Administration
Maternal and Child Health Bureau